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ABSTRACT

In the executive report to the 1990 annual report the Virginia Board for Rights of the Disabled summarizes findings from the analysis of 47 federally-assisted and state-funded programs serving individuals with developmental disabilities in Virginia as well as a consumer satisfaction survey polling 309 Virginians with developmental disabilities. Recommendations pertain to education, employment, community living, and unserved/underserved constituencies with developmental disabilities, with recommendations made in each category. Implementation and advocacy plans for the board are also described. (PB)

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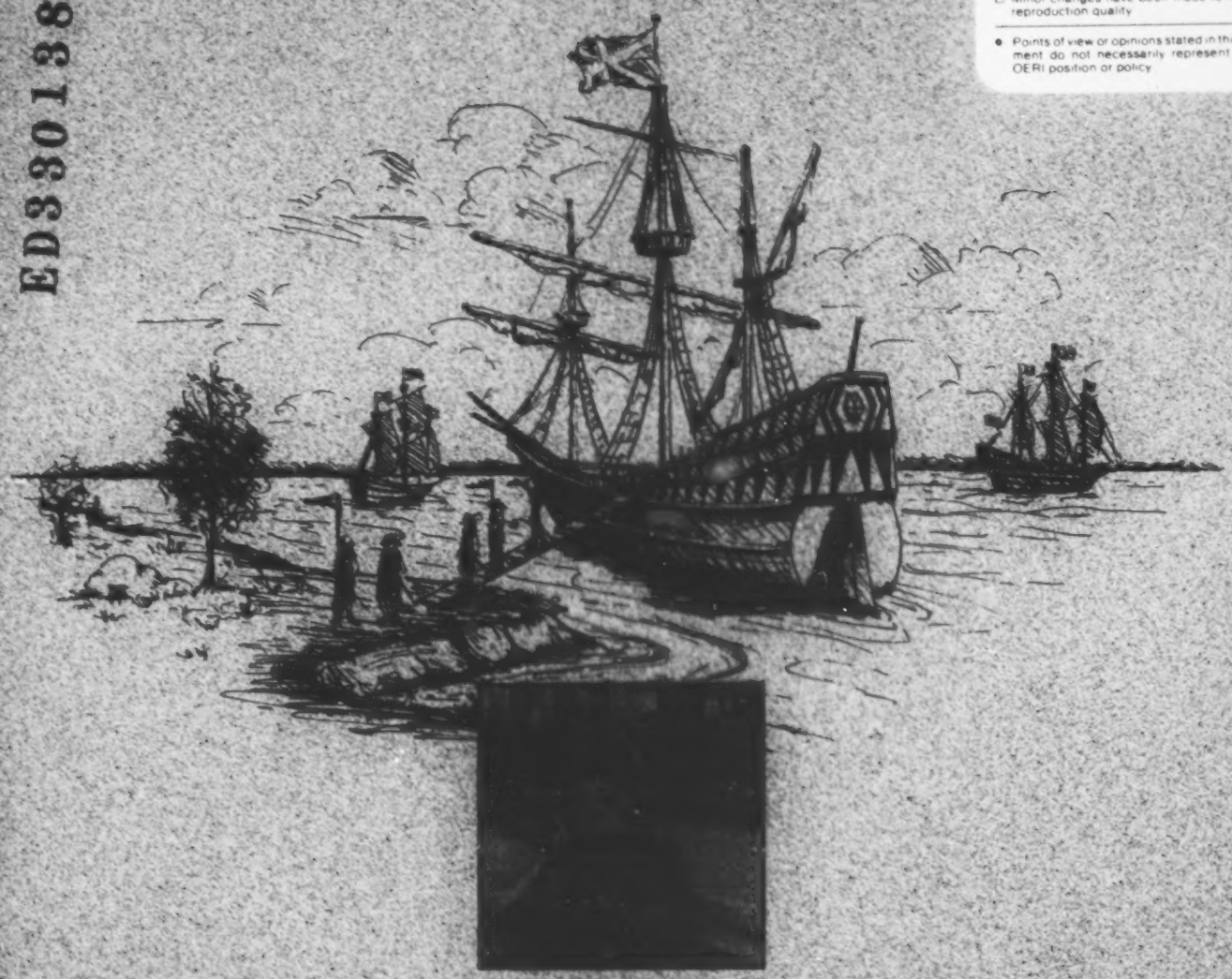

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INDEPENDENCE
THE JOURNEY CONTINUES

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COMMONWEALTH of VIRGINIA

Board for Rights of Virginians with Disabilities
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Richmond, VA 23219
(804) 225-2042

Dear Governor Wilder:

It is with great pride that the Board for Rights of Virginians with Disabilities presents "Independence - The Journey Continues." This document is a summary of the Board's 1990 Report. Public Law 100-146, "The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987" required each state to develop a comprehensive multifaceted report for submission to its governor, state legislature, and the Administration on Developmental Disabilities.

Our report provides direction for establishing policies in Virginia to enhance the independence, productivity and community integration of persons with developmental disabilities.

The Board acknowledges the countless hours devoted over two years by agency personnel, consumers, families, and local leaders to develop this report. They shared their visions for the report. Their input was received through public hearings, surveys, workgroups, and broad-based committee deliberations. They continue to assist the Board in the development of strategies to implement each of the recommendations contained herein. The Board anticipates communicating its implementation plans to you in the near future.

The visions expressed by Virginia's founding fathers are not yet a reality for all citizens with developmental disabilities. Consumers, legislators, policy-makers and citizens have a responsibility to move Virginia closer to those visions.

As you stated in your inaugural address, ". . . disability can be overcome . . . we have come far, but we have far to go." Together we will ensure full citizenship, independence, productivity, and integration for all Virginians with disabilities.

Sincerely,

Maureen S. Hollowell

Maureen S. Hollowell,
Chair

"Independence, The Journey Continues"

Executive Summary — 1990 Report on Persons with Disabilities

Board For Rights of Virginians With Disabilities

This summary is a synopsis of the recommendations in the Board's 1990 Report. The complete text of the Report is important to fully understand the intent and importance of the recommendations. The complete report and detailed analyses in Appendix A, "Analysis of the Federally-Assisted and State-Funded Programs serving individuals with Developmental Disabilities in Virginia" and Appendix B, "Life Patterns," a summary of the Consumer Satisfaction Survey are available upon request. For more information, please contact:

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What are Developmental Disabilities?

Persons with developmental disabilities have severe, chronic conditions that:

- are attributable to a mental or physical impairment or combination of mental and physical impairments;
- are manifested before the person attains age 22;
- are likely to continue indefinitely;
- result in substantial functional limitations in three or more of the following areas of major life activities:
  1. self-care
  2. receptive and expressive language
  3. learning
  4. mobility
  5. self-direction
  6. capacity for independent living
  7. economic self-sufficiency
- reflect the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are lifelong or of extended duration and are individually planned and coordinated.

Independence is being allowed the right to make choices and exercise control over your life.

Productivity is, through work or activities, the opportunity to make a contribution to the community.

Integration is participating in the richness of life within society, not apart from it or on the sidelines.

Introduction

Empowerment becomes more than just a word for the Virginians demonstrating their support for the Americans with Disabilities Act on Washington, D.C.

Photo by Maureen Hollowell

> ***We need to rid ourselves in community efforts of the old mind-set that DD persons are somewhat sub-human and that substandard living is good enough for them. They are capable of having jobs and should take vacations and enjoy recreation as much as the rest of us.***
> *(Comment received at public hearing)*

Overview

This report is about Virginians for whom Thomas Jefferson's vision of individual right to life, liberty, and the pursuit of happiness has yet to become a reality.

For many Virginians, reality is the physical or mental differences that are the focus of their individuality instead of the individual rights and values written some 200 years ago in the basic charters of our nation.

In preparing this report we talked to people with disabilities and people who provide services to these people. Our research has only substantiated what some have already known through their daily life experiences:

- significant numbers of people with a developmental disability are isolated,
- they struggle with serious financial problems,
- they stand outside the mainstream because of public acceptance, little training, and a lack of services,
- they are often told what to do instead of being asked what they want or need,
- they are erroneously considered to be unproductive, and
- they are frequently shown little respect and are treated without dignity.

Each Virginian has a different reaction to these facts. Some are angry; others are sad. Many feel helpless and others feel frustrated. Some deny the existence and plight of Virginians with disabilities. It is our hope that after reading this document such denials will be removed and all the citizens of Virginia will work together to achieve the visions of our forefathers for people with disabilities.

The recommendations contained in this report are long term initiatives. They provide direction in Virginia for establishing appropriate policies and effective service delivery that will enhance the independence, productivity, and community integration of persons with developmental disabilities. They are the foundation for our joint efforts to make Jefferson's vision become reality.

Basis of the Report

"All persons with developmental disabilities should receive the services and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity and integration into the community."

This statement found in the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146) provides both a challenge and a vision for Virginia. Although Virginia has made great strides towards this goal, the vision expressed by Congress is not yet a reality for all Virginians with developmental disabilities.

Under P.L. 100-146, the Board for Rights of Virginians with Disabilities was mandated to ask all of the major stakeholders about services for people with developmental disabilities. Special attention was paid to people who are not receiving services or are not getting appropriate or adequate services (called, for the purposes of this report, the unserved/underserved). Individuals and their families, advocates, policy makers, and service providers were asked several key questions:

- Who is getting services funded by public dollars?
- How can we ensure that public dollars support programs and services that promote independence, productivity and integration instead of dependency and segregation?
- Why are so many people with developmental disabilities still left out of the services system despite huge expenditures?
- What are those services and what are their goals? Are these goals appropriate and are the service dollars achieving these goals?
- What do people with developmental disabilities say about these services?
- What policy changes are needed to solve problems, expand services or change our systems for greater effectiveness?

Process

In 1988 the Board developed a work plan that centered around two surveys and several work groups. Fifty consumers and family members were trained as surveyors to interview 309 people with disabilities for a Consumer Satisfaction Survey. Every Federally-assisted and state-funded program which serves people with disabilities was also surveyed. Consumers, family members, public and private service providers, and state agency representatives developed critical issues through work groups which focused on unserved/underserved, community living, education, and employment. From the discussion of the critical issues came the recommendations of the work groups which were distributed statewide for public comment. The recommendations were modified to accommodate the extensive comments received. The report was approved by the Board in November 1989. An overview of the survey findings and work group results are presented in the following pages.

> ***Maintaining dignity is a basic need for economically strapped families.***
> *(Comment received at public hearing)*

Lift equipped buses allow these women to accomplish their daily responsibilities independently.

Photo by R. Dementi

Workgroups

Critical Issues—Unserved/ Underserved

- The availability of services is often dependent upon type of disability.
- Documentation concerning the numbers of people with disabilities or their service needs is frequently absent or collected in a manner which limits its usefulness.
- Interagency collaboration to meet complex service needs is rare.
- There is an absence of designation of agency responsibility for some disabilities, and in some cases, a lack of enforcement of agency responsibility where the mandate does exist.
- There is inadequate funding for services and supports for Virginians with disabilities.

Critical Issues—Community Living

- Consumer empowerment for making life choices is rarely permitted by service providers.
- The community services and supports which are available are insufficient, inadequate, or inappropriate.
- Case management services are lacking in quality and availability, and often recommend only the services available from the case manager's employer.
- There is a lack of accessible and affordable transportation. Paratransit is often pitted against fixed route services at the local level.
- The absence of an array of affordable and accessible housing, including supervised apartments, often forces people with disabilities to live in restricted settings such as institutions, large group homes, and homes for adults.

Critical Issues—Education

- There is a continuing concern that mechanisms for monitoring compliance are insufficient and inadequate to assure uniform adherence to special education standards.
- There are insufficient numbers of appropriately trained educators, administrators, and related services personnel.
- Students with developmental disabilities are exiting the school system (e.g., aging-out) without the skills or experience necessary to maximize their current or future independence, productivity, and integration into community life.
- The majority of students with developmental disabilities have very little contact with peers who do not have disabilities.

Critical Issues—Employment

- There are insufficient and inadequate services and supports to facilitate appropriate productive employment for persons with disabilities.
- There are inadequate efforts to promote the ability and availability of persons with developmental disabilities for meaningful and productive employment.
- People with disabilities have limited choices in the type and level of employment.

Consumer Satisfaction Survey

Three hundred and nine Virginians with developmental disabilities (encompassing mental illness, cognitive, physical, and sensory disabilities) were interviewed by trained surveyors with disabilities or their family members.

They were asked about:

- experience and satisfaction with programs and agencies, past and present
- reasons for dissatisfaction with services
- current needs for additional or different services
- reasons why needed services were not being received
- satisfaction with their lives, school, jobs and where they lived
- independence, productivity and integration into the community, and their importance

What they said:

- People with developmental disabilities are dissatisfied with sitting on the sidelines of life. They want to be active and integrated members of their communities.
- Adequate financial resources would allow people with disabilities to become independent, productive, and integrated into their community.
- People with different disabilities report varying levels of satisfaction with, need for, and availability of services.
- Lack of employment is a major barrier to quality of life for many persons with developmental disabilities.
- The social support networks of most people with disabilities are very limited.
- The independence of persons with developmental disabilities is often limited by the vested interests of the service delivery system, or by primary caregivers who may not be aware of the importance of early independence and therefore limit such opportunities.
- Adequate supports and services are not available to assist families to encourage future independence of their children with disabilities.
- Because of low expectations and limited opportunities for social interactions, many people with disabilities are isolated and rarely experience the joys of marriage and children.

Federally-Assisted and State-Funded Programs

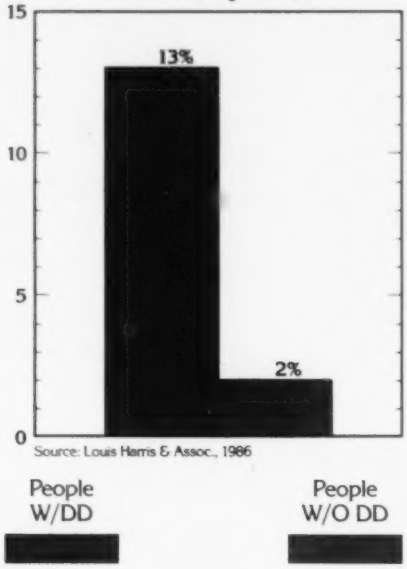
To assess Virginia's efforts to promote the independence, productivity, and integration of its citizens with developmental disabilities and to identify groups of individuals currently unserved or underserved, the Board conducted an analysis of 47 federally-assisted and state-funded programs operated by eleven state agencies. Key findings are:

Unlike most people with disabilities, this women not only holds a full time job, but experiences both the pleasures and responsibilities of parenthood.

Photo by Richmond Newspapers Staff

> ***My son wants to desperately engage in adult activities. He wants a girl friend or a wife and his own home, even children.***
> *(Comment received at public hearing)*

People Who do Not Go To The Grocery Store



> ***It seems cruel to give a kid a wheelchair that he can only use at home because the locality cannot provide accessible transportation.***
> *(Comment received at public hearing)*

- Significant gaps remain in Virginia's network of services for individuals with developmental disabilities. Many individuals are unable to access services they urgently need to promote their independence, productivity, and integration.

Individuals with cerebral palsy, epilepsy, traumatic brain injury, autism, orthopedic impairments, spina bifida, and many other disabilities are unable to access case management, housing, personal assistance, and other services because no state agency has a legislative mandate to provide these services. As a result, persons with developmental disabilities who are not mentally disabled comprise the largest group of unserved and underserved individuals in the state. In addition, a number of state services are presently underutilized by individuals with developmental disabilities because the supports needed to get the services are unavailable.

- Geographic location often determines the services available to people with disabilities.

Even where state agencies have a mandate to provide services to individuals with developmental disabilities, housing, independent living, family support, personal assistance, accessible transportation, and case management services are in critically short supply, especially in rural areas and in localities unable to supplement federal and state funds with local monies.

- Virginia has not moved rapidly to implement the concept of least restrictive environment as a guiding principle of its service delivery system and relies heavily on program alternatives that are neither appropriate nor cost effective in the long run.

The mission statements of most state agencies embrace the concept of least restrictive environment to enhance the independence, productivity, and integration of individuals with developmental disabilities. However, the Commonwealth's service delivery system continues to dedicate massive resources to service alternatives such as institutions that are viewed by many people with disabilities as overly restrictive and segregated.

- Virginia's efforts to evaluate the effectiveness and efficiency of services provided to individuals with developmental disabilities are not systematic or comprehensive, nor do they regularly include input from those who receive the services.

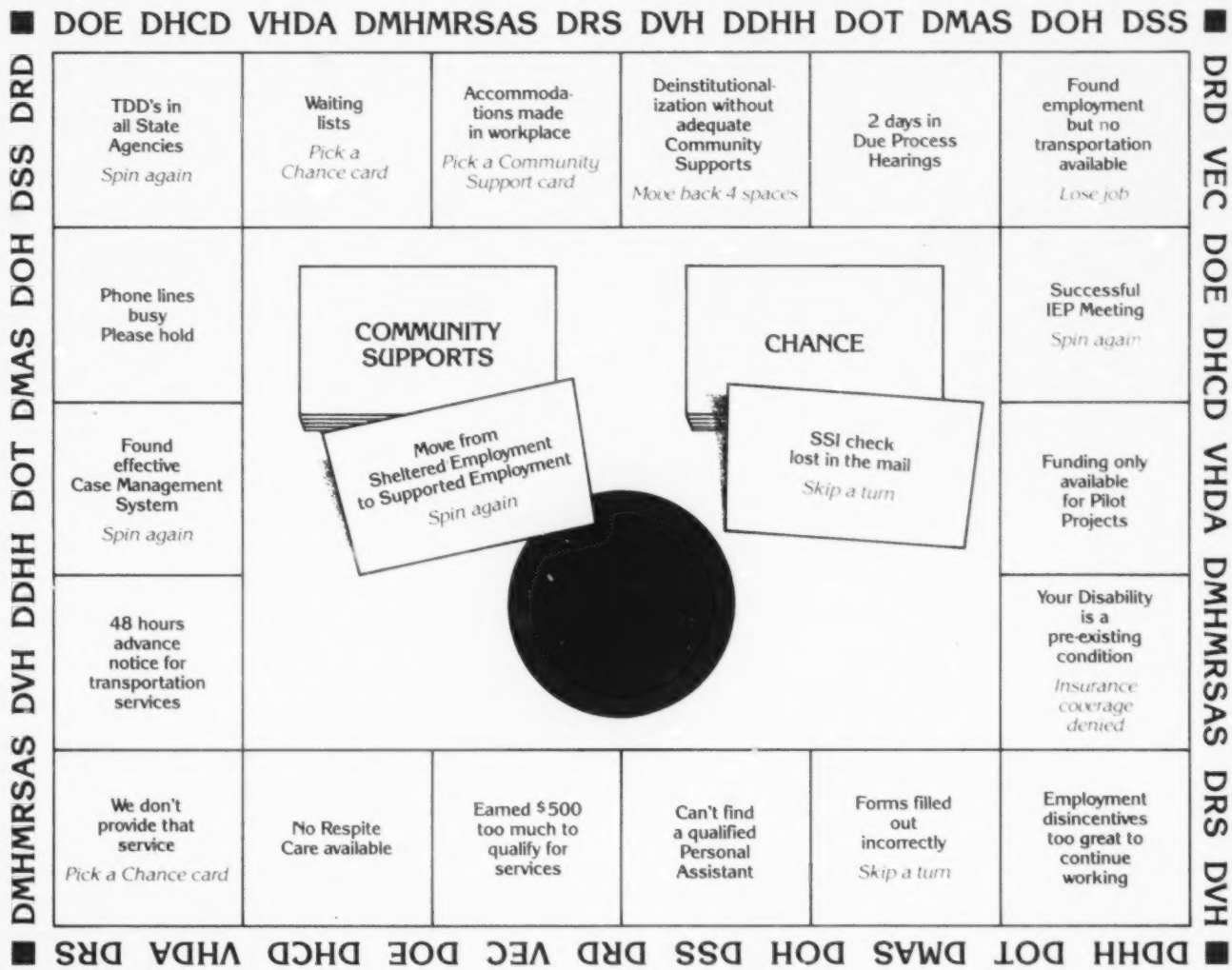
The lack of systematic efforts to evaluate the quality of services provided to people with disabilities is a universal problem across all state agencies. Particularly striking is the lack of input from people with disabilities into the planning and evaluation of services. Generally existing evaluation approaches are quantitative, rather than qualitatively examining improvements in life activities.

Disability Is Not a Game

This game board illustrates many of the experiences of people with disabilities as they attempt to get services and supports. Unlike games produced by toy manufacturers, this game is no fun.

The alphabet soup surrounding the board represents the many state agencies a person might encounter in his quest for services. Similar to the search for services, there is no clear starting point on the board. Age, income, level of functioning, and type of disability affect the services for which one might be eligible. There are disability-specific agencies as well as generic agencies which provide services to persons with disabilities.

No single State or local agency is responsible for serving all persons with developmental disabilities nor is this necessarily desirable. What is desirable is an equally available array of services regardless of disability, geographic location, or other variables.


DOE DHCD VHDA DMHMRSAS DRS DVH DDHH DOT DMAS DOH DSS
DRD DSS DOH DMAS DOT DDHH DVH DMHMRSAS
DRD VEC DOE DHCD VHDA DMHMRSAS DRS DVH
DDHH DOT DMAS DOH DSS DRD VEC DOE DHCD VHDA DRS
TDD's in all State Agencies
Spin again
Waiting lists
Pick a Chance card
Accommodations made in workplace
Pick a Community Support card
Deinstitutionalization without adequate Community Supports
Move back 4 spaces
2 days in Due Process Hearings
Found employment but no transportation available
Lose job
Phone lines busy Please hold
COMMUNITY SUPPORTS
Move from Sheltered Employment to Supported Employment
Spin again
CHANCE
SSI check lost in the mail
Skip a turn
Successful IEP Meeting
Spin again
Found effective Case Management System
Spin again
Funding only available for Pilot Projects
48 hours advance notice for transportation services
Your Disability is a pre-existing condition
Insurance coverage denied
We don't provide that service
Pick a Chance card
No Respite Care available
Earned $500 too much to qualify for services
Can't find a qualified Personal Assistant
Forms filled out incorrectly
Skip a turn
Employment disincentives too great to continue working

Recommendations—Unserved/Underserved

Agencies should recognize parents to be capable, willing and agressive care givers for their children. In that light, such agencies should be created to assist families.
(Comment received at public hearing)

Beth's Reality in Virginia

After seeing many pediatricians and specialists, Beth was finally diagnosed as autistic. Doctors recommended that she be institutionalized, but Beth's parents wanted to keep their daughter at home. Her mother quit her job because they could not find day care or respite services willing to accept Beth or knowledgeable enough to care for her.

Beth's parents tried to get services for her, but no agency is mandated to serve people with autism. There were no programs or services in Beth's community. She started school in a special education class, but due to their lack of training, the teachers were unable to control her maladaptive behavior.

After six years without any respite, vacations, or evenings out, Beth's parents were exhausted and unable to cope. Their remaining option was to send Beth to a residential school five hours away. After a long due process hearing, the school system agreed to pay for a residential placement.

Beth will soon be 22 and her parents are concerned about her future prospects. Beth had access to communication devices at her school, but they are too expensive for her parents to purchase for her future use. There are three-year waiting lists for the group homes in the area and her parents are not certain that the staff in these homes have sufficient knowledge about autism to work well with Beth. Although she has limited vocational skills, the staff at the workshop are also not trained sufficiently in autism to provide the support Beth's needs.

Virginia's Vision

Beth was diagnosed at a very young age as having autism. Beth's parents sought case management services from Case Managers Unlimited, a non-profit organization. This service, like many others needed by Beth and her family, is purchased through a state-wide voucher system which enables their selection of appropriate services for Beth.

Beth's case manager began with family education. She helped Beth's parents and siblings understand what autism meant and how it affected Beth and them. She also assisted the family to arrange services for Beth, including school, after school and summer recreation programs, transportation, family support, respite services and financial assistance. All of these services were found in their locality.

When Beth became 22, it was a time of celebration. She moved into a group home with three other women. Highly trained staff help her to learn such tasks as meal preparation and transportation to work. Beth's communication devices, (i.e. her "day planner" which includes photographs detailing her schedule) facilitate her communication with persons not knowledgeable about autism. The case manager, residential staff, job coach, and Beth meet regularly to identify and coordinate the supports she needs to continue to function in her community.

Recommendations

(1) The Secretary of Health and Human Resources and the Board for Rights of Virginians with Disabilities should identify and address through the Plan of Cooperation the service needs of constituencies with developmental disabilities who are currently unserved/ underserved.

(2) The General Assembly should authorize and provide funding for a legislative study to determine the agency(s) responsible in Virginia to provide and coordinate comprehensive services for all persons with developmental disabilities, based upon the federal definition in the Developmental Disabilities Act.

(3) The General Assembly should formally delineate the responsibility of all existing State and Federally-assisted agencies and programs to accommodate persons with developmental disabilities with appropriate services and supports.

(4) The General Assembly should provide sufficient funding and allocate appropriate manpower to enable significant growth in the human services system in Virginia. New specialized services and supports must be developed, financed, implemented, and monitored to meet the needs of Virginia's unserved/underserved population of persons with developmental disabilities.

(5) The General Assembly should provide the Department of Rehabilitative Services with adequate funding and manpower to operationalize its legislative status as the State agency responsible to provide and coordinate services and case management services for persons with functional and central nervous system disabilities.

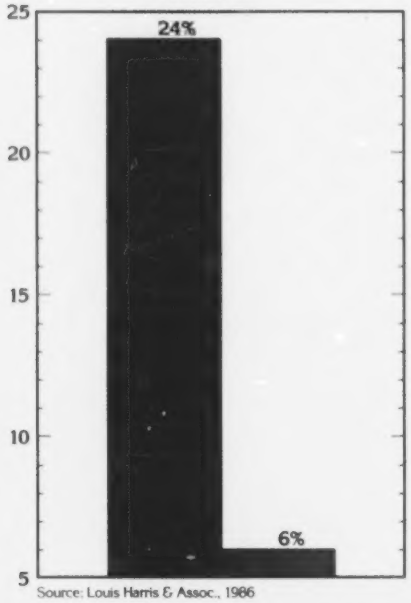
(6) The General Assembly should require and provide funding for a coordinated statewide data base on disability to be established and maintained. This base of information must include extensive data about the characteristics and service needs of persons with disabilities, detailed information about relevant programs and services provided by state and local agencies, and employment information.

(7) The General Assembly should require all State- and Federally-assisted programs in Virginia to adopt and uniformly operationalize a consistent definition of services and eligibility criteria for disability programs.

(8) The General Assembly should require all State and local agencies which receive public funds to establish and maintain waiting lists of people requesting services who are not being served or who desire additional services in order to provide data for planning, evaluation, and program development activities.

Case management should be consumer directed with consumers defining needs, services, outcomes and quality.
(Comment received at public hearing)

Expressed Dissatisfaction With Life



Source: Louis Harris & Assoc., 1986

> ***Financial ability to purchase adaptive equipment, mobility aids, etc., and knowing where to find the right equipment can mean the difference between dependence and independence for a physically disabled person.***
> *(Comment received at public hearing)*

Frank's Reality in Virginia

Frank is an adult with cerebral palsy, above average intellectual ability and severe physical limitations. When he became 22 his aging parents did not feel that they could adequately care for him. His case manager recommended placement in a home for adults. Although the residence is in his city, it is not close enough to his home for his parents and friends to visit him and for him to participate in his community. After ten years at the home, Frank is bored, frequently depressed and, at times, very uncooperative.

In the adult home, Frank depends on staff for virtually everything. He cannot afford an electric wheelchair, thus he is not independently mobile. When Frank asks staff about technological supports, they are unaware of what is available, and always respond that it is too expensive anyway.

Virginia's Vision

Frank decided how he wanted to live and how he could be productive. His case manager helped him to get the supports he needs to live independently. He lives with a personal assistant in the community where he grew up, close to his friends and family. His apartment, the pool, and the recreation center are accessible. He sees his family regularly, enjoys relationships with his neighbors at the apartment complex, and participates in weekly social events.

Frank has many technological aids which he was able to test for their suitability prior to purchase through Medicaid.

When Frank wants to visit friends or relatives who do not live on the accessible bus route, he uses the paratransit service. This service will accommodate his request up to an hour before his scheduled departure.

Recommendations

Consumerism

(9) The Governor should promote and monitor self-advocacy and consumer empowerment in all public agencies by requiring, through an Executive Directive, that there be continuous consumer participation in decisions concerning the planning and implementation of services for individuals with disabilities.

(10) The General Assembly should establish and make uniformly available a state-wide system of case management services for persons with developmental disabilities that is independent from agencies which directly fund and provide services. Case load sizes should be limited to 20 - 40 persons to allow individualized, consumer-directed services.

(11) The General Assembly should establish and make uniformly available throughout the State a quality assurance system that is independent from agencies which directly fund or provide services, that actively involves consumers with developmental disabilities and their families, and that evaluates programs and services with criteria of individual outcomes relating to independence, productivity and community integration.

(12) The Department for Rights of Virginians with Disabilities should collaborate with Centers for Independent Living and disability advocacy organizations to sensitize and educate health care personnel in appropriate interaction with persons with developmental disabilities and their families in the use of existing information and referral services.

Increased Services and Supports

(13) The General Assembly should require the Department of Medical Assistance Services to work collaboratively with appropriate State and local agencies to determine the feasibility of expanding the scope and increasing the individuals eligible to participate in all aspects of the Medicaid program, particularly to increase opportunities for community-based habilitation and rehabilitation services needed by persons with developmental disabilities.

(14) The General Assembly should provide permanent funding to significantly expand and make uniformly available supported employment, independent living, rehabilitation engineering and assistive technology services. The administration and implementation of these services should be coordinated among appropriate state and local agencies.

(15) The General Assembly should require and provide funding to establish and make uniformly available a statewide personal assistance services (PAS) system of consumer-directed, individualized supports necessary to promote the maximum independence and productivity of individuals with developmental disabilities. This system would provide attendant services to assist in accomplishing activities of daily living; it would include financial and technical assistance to obtain adaptive equipment, communication devices, and mobility aids which maximize individual functioning.

(16) The General Assembly should establish State tax credits or deductions for families or individuals who provide a home and supervision or care for family members or other person with developmental disabilities, if such living arrangement and care represents the "least restrictive environment" available during the applicable tax year.

(17) The General Assembly should require and provide funding to establish a multifaceted system of family support services (FSS) to be uniformly available throughout the state for all persons with developmental disabilities. This flexible system would respond to changing individualized needs of families; it would include direct support services, stipends and vouchers to purchase or obtain services, and financial and technical resources to obtain adaptive equipment, communication devices, and mobility aids which maximize individual functioning.

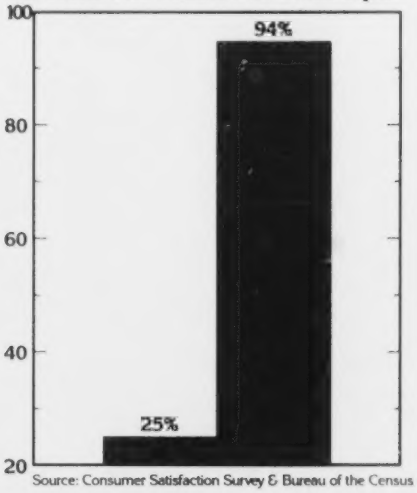
(18) The General Assembly should support the establishment and maintenance of local or regional family support resource centers throughout the state. These would provide centralized information about and referral to local and regional programs and services for persons with developmental disabilities, planning and problem solving consultation, counseling and specialized training for family members and/or primary caregivers, and respite services.

An instructor with a disability at the Triple R Ranch in Chesapeake teaches children with disabilities in the therapeutic riding program.

Photo by RRR Ranch

> ***Why the development of home-based services is slower is a puzzle as these are so much more cost-effective, not to mention more humane.***
> *(Comment received at public hearing)*

People Who Own Their Home Or Hold The Lease For Their Apt.



Source: Consumer Satisfaction Survey & Bureau of the Census

> ***If you have no place to live, what good are other services?***
> *(Comment received at public hearing)*

Housing

(19) The Board of Housing and Community Development (HCD) should insure compliance with the federal Fair Housing Amendments Act of 1988 through the Uniform Statewide Building Code and provide continuing education and training for building designers and inspectors on adaptable design and accessibility.

(20) The General Assembly should establish and fund a rental assistance program for persons with disabilities who meet low income criteria.

(21) Agencies of State government that provide housing and other services to persons with disabilities and disability advocacy organizations should work collaboratively with the housing industry to make residences and appropriate support services, including personal assistance, available to people with disabilities.

(22) The Department of Housing and Community Development should expand financial and technical assistance for modifying existing housing units to increase accessible housing opportunities for persons with disabilities.

Transportation

(23) The General Assembly should provide incentive funding for localities to promote purchase of lift-equipped buses and to encourage continuation and expansion of other transit services which promote mobility and independence for Virginians with disabilities. In addition, uniform equipment standards should be required by the Department of Transportation.

(24) The General Assembly should require formal transportation coordination agreements to be developed and implemented among local providers of transportation services, especially in rural areas.

(25) The Department of Transportation should provide funding to develop and implement an ongoing program of training for users who have disabilities and providers who serve riders on public transportation systems.

(26) The General Assembly should establish and fund a voucher program to enable individuals with developmental disabilities to obtain transportation services needed to get to work, receive services, perform daily activities, or participate in community activities.

Personnel Preparation

(27) The Secretary of Education and the State Council on Higher Education should direct Virginia's institutions of higher education to expand and initiate new programs of pre-service and interdisciplinary training to prepare professionals and paraprofessional to deal with the assessment, training, and other service delivery needs of persons with developmental disabilities.

(28) The General Assembly should require and provide funding for a statewide system of personnel support which includes inservice training and programmatic technical assistance for professionals and paraprofessionals who participate in the public/private developmental disabilities service delivery network.

Prevention

(29) The General Assembly should require and promote implementation of primary, secondary, and tertiary prevention strategies to minimize the occurrence of conditions or mental and physical impairments which may result in developmental disabilities.

Recommendations—Education

Brad's Reality in Virginia

Brad is a twelve year-old who has spina bifida and a learning disability. Each day the bus ride to school is an hour-long ordeal for Brad, who often arrives late. When Brad gets to his center-based school, he goes directly to his classroom which is in a separate wing of the school. The only contact he has with non-disabled students occurs during school assemblies and in the cafeteria. Brad cannot participate in the after school programs because none of the recreation workers are trained to work with children who have physical disabilities.

There are ten children with differing disabilities in Brad's class, yet the teacher does not have an aide. His teacher is certified in mental retardation, and is working towards a certification in learning disabilities. The only knowledge she has about Brad's spina bifida has come from his parents.

Brad is still using last year's individualized education plan (IEP). Although its development was a struggle and it appeared to be a battle won, all the listed services are not being provided. Brad's parents feel that he needs physical therapy three times a week, but the school division can fund these services only once a week.

Virginia's Vision

Each morning Brad rides to school on a lift-equipped bus. He is mainstreamed with age appropriate peers for four of his six classes. Each of his teachers has attended training which enables them to help Brad compensate for his learning disability. They also understand spina bifida and how it affects Brad's functioning. All of the generic school personnel who come into contact with Brad have received inservice training on special education and disability issues. All of Brad's special education teachers are certified in the area in which they teach. The technological supports that Brad needs are readily available. The other children accept Brad, understand his disabilities, and respect his extraordinary ability to play the piano. Last year he played a song at the PTA Spring performance.

Once a year, Brad, his parents, teachers and another representative from the school meet to formulate his IEP. This group decided to meet in January and June to evaluate Brad's progress. The IEP contains goals and objectives which address his academic and vocational needs as well as his mobility, self-esteem, social and leisure skills development.

> ***The Dept. of (Special) Education should wake up to the fact that for many disabled students, summer vacation is not a treat, it is a time of waste & regression.***
> *(Comment received at public hearing)*

Recommendations

Appropriate Programs and Services

(30) The Department of Education should enforce implementation of "Standards of Quality" for the delivery of special education and related services by local education authorities. Persons with developmental disabilities, parents and other family members, and disability advocacy organizations should have active participation through public comment opportunities and the legislative process in future revisions of these "Standards of Quality"

(31) The Department of Education should aggressively monitor and follow through with implementation of corrective actions plans with local education authorities to insure uniform compliance with the intent and requirements of P.L.94-142.

Technology allows this high school student the opportunity to maximize his educational opportunities and enter into adult community life.

Photo by Allen Jones

> ***Many teachers are willing to cooperate (with integrated classrooms) but are uncomfortable about how to handle this population due to lack of training.***
> *(Comment received at public hearing)*

(32) The Department of Education should implement policies and regulations to insure that all children and youth with developmental disabilities are educated to the maximum extent possible and appropriate with non-disabled peers and within their home communities. A full range of appropriate placement options should be available.

(33) The Department of Education should increase its efforts to assure the employment of sufficient numbers of appropriately trained and certified special education teachers and related services personnel by local education authorities.

(34) The Department of Education should provide the technical assistance necessary to assure that educational standards and regulations are appropriately implemented. Particular areas needing attention are academic and functional curricula, assistive technology, vocational training, and leisure skills training. These areas should be directly reflected in individual education plans for children and youth with developmental disabilities.

(35) The Department of Education should establish, monitor, and enforce favorable caseload standards to assure that the needs of children and youth with developmental disabilities are met with appropriate special education and related services.

Personnel Preparation

(36) The Department of Education should strengthen its policies and procedures for the certification and re-certification of teachers, administrators, and other educational personnel to address the appropriate preparation of both "special education" and "related services" personnel and "regular education" personnel to work effectively with children and youth with developmental disabilities. Local education authorities should aggressively work to recruit and employ qualified personnel with disabilities.

(37) The Department of Education should establish specific certification categories for teachers qualified to teach children and youth with autism, children and youth with traumatic brain injury, and children and youth who are multihandicapped. Teacher preparation programs in these areas must be established.

(38) The Secretary of Education and the State Council on Higher Education should direct Virginia's institutions of higher education to expand and initiate new programs of appropriate education and preservice training for teachers and related services personnel to become qualified and certified to provide special education and related services needed by children and youth with developmental disabilities.

Preschool and Postschool Transition

(39) The General Assembly should establish funding specifically to promote a comprehensive, coordinated, interagency system of services for children ages 0 - 2 years with developmental delay or those with a diagnosed condition or subject to environmental factors which have a high probability of resulting in delay.

(40) The General Assembly should require and provide funding for a formal statewide transition effort to promote collaborative activities between school divisions and community service agencies to provide for transition planning and delivery of transition services for youth with developmental disabilities who are exiting school and entering adult community life.

Recommendations—Employment

Diane's Reality in Virginia

When Diane, a young adult with mental retardation, became 22 years old, she "aged out" of her special education program without having received any sort of vocational education. Diane was on a state agency waiting list for vocational services for the next three years. She sat at home, watched television, and waited.

After three years without any socialization and limited intellectual stimulation, Diane had regressed in many areas. After another nine months on the waiting list, she was placed in a sheltered workshop. She quickly became bored with the simple repetitive task of stuffing envelopes. Her hourly earnings are below the federal minimum wage. Although she now has an activity during the day, Diane's parents must provide her transportation because there are no public transportation services in the community.

Diane cannot afford, nor is she prepared, to live on her own.

Virginia's Vision

Diane, a 25 year-old with mental retardation, graduated from the special education program at her local high school. The last four years of her education included an emphasis on the transition from school to the workplace. Diane was able to try three different work experiences and decided to pursue her interest and skills in botany.

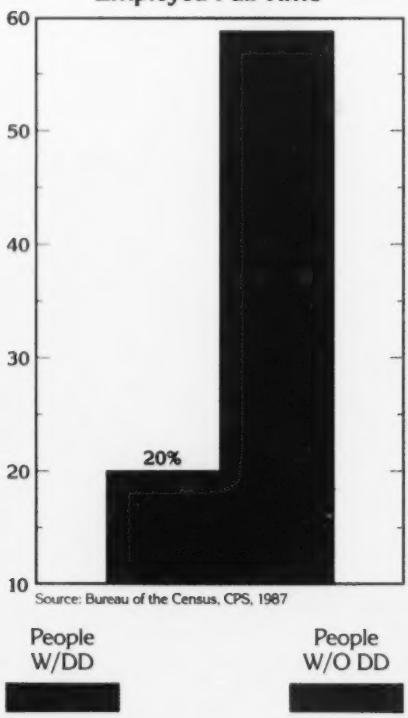
Through the Commonwealth's Job Match program, Diane has spent the last three years working in a greenhouse, which received state job tax credits during the first year of Diane's employment. Although her original responsibilities were in plant cultivation, she was transferred recently to customer service due to her knowledge of plants and desire to share this information with others.

Diane receives vouchers from the state in order to purchase transportation services. Her job coach visited her on a monthly basis during the first year of her employment and remains in contact with her regularly.

With adequate supports such as this service dog, people with disabilities can be independent, productive members of their communities.

Photos by Richmond Newspapers Staff

People Who Are Employed Full-Time



Our son lives at home still, although he is 32 years old. We have discussed independent living, but because there is no dependable transportation to his job, we cannot consider it at this time. His job is the most important thing to him and he would not consider jeopardizing it by not being able to get there.
(Comment received at public hearing)

Recommendations

(41) The General Assembly should provide sufficient permanent funding to expand and maintain long term supported employment opportunities for persons with severe physical, sensory, and mental disabilities. This should include funding to provide for appropriately trained personnel necessary for supported employment activities.

(42) The General Assembly should provide incentive funding to encourage rehabilitation facilities and sheltered workshops to develop and expand community supported employment opportunities.

(43) The General Assembly should mandate the implementation of a coordinated, interagency job-matching, placement and follow-along system for persons with disabilities. This system should include the collaborative efforts and participation of all appropriate publicly supported State and local agencies and programs.

(44) The General Assembly should provide funding for a voucher system to purchase needed ancillary support services (e.g. transportation, procurement of adaptive equipment, mobility aids, or communication devices, child care, etc.) to facilitate employment and promote the independence of individuals with developmental disabilities.

(45) The General Assembly should create State tax incentives which will benefit employers who hire and provide long-term supports which enable persons with developmental disabilities to maintain remunerative employment.

(46) Local education authorities and community agencies should work collaboratively with the Department of Education using "Virginia's Plan of Coordinated Transitional Services for Youth and Young Adults with Disabilities" to educate students with developmental disabilities, family members, employers, and the public concerning the employment potential of individuals with developmental disabilities.

(47) The General Assembly should require the Secretary of Administration and the Department of Personnel and Training to strengthen Virginia's commitment to affirmative action in hiring and promoting persons with disabilities within all areas of State government through explicit directives, education and monitoring.

From Visions To Reality—Implementation Plan

The preceding 47 recommendations offer direction for maximizing the potential and improving the quality of life for Virginians with developmental disabilities. It is important to remember that these goals are long term initiatives that can not occur overnight. The recommendations incorporate a multi-tiered approach toward achieving systems change over a number of years.

To focus attention on these important recommendations, the Board has developed the following strategies:

- To provide information to state and local policymakers and advocates on methods for implementing the recommendations;
- To commend these recommendations and strategies to consumer and advocacy organizations for incorporation into their plans and activities;
- To assist the Governor to host a conference on disabilities to educate elected and appointed officials about the recommendations, empowerment, and self-advocacy;
- To provide education to the general public on this report, its findings, recommendations, the abilities of people with disabilities, and strategies to implement change.

The Board plans to develop specific implementation actions for each of its 47 recommendations. These strategies will be available in October, 1990.

Photo by Lou Cordero

Program accessibility allows this student to participate in college life, but structural barriers still prevent full integration.

> ***Great report, now let's translate the findings into action.***
> *(Comment received at public hearing)*

Responsibilities of the Board for Rights of Virginians with Disabilities

The Board for Rights of Virginians with Disabilities is an independent body created by the Virginians with Disabilities Act. The Board serves a dual role in Virginia. In its role as Virginia's Developmental Disabilities Planning Council, the Board is federally mandated to advocate for persons specifically with **developmental** disabilities. Through its state mandate, it serves as an advisory body to the Governor through the Secretary of Health and Human Resources on the needs of Virginians with **all** disabilities. Although this report specifically focuses on persons with developmental disabilities, it is the Board's belief that if services and supports are available for persons with developmental disabilities, the needs of persons with other disabilities will also be met.

The Board is composed of 40 members who are appointed by the Governor. In addition to agency heads, and representatives from manufacturing, commerce, higher education, local government, real estate and transportation, at least 51% of the membership must be persons with disabilities and parents of persons with disabilities.

The Board meets quarterly and all meetings are open to the public. Committees address specific issues that involve disability policy, issue awareness, and advocacy in the areas of education, employment, health, housing, planning, and transportation. A steering committee, comprised of officers and the six committee chairs, meets between Board meetings.

The Board has the responsibility to:

- advise the Governor and Secretary of Human Resources on issues of relevance to persons with disabilities;
- submit a biennial report to the Governor on the needs of persons with disabilities, the success of state agencies in meeting these needs, an economic and cost benefit report on the impact of services to person with disabilities;
- review and submit annually a state plan to the Governor and the federal Secretary of Health and Human Services;
- review and comment upon state plans which affect persons with disabilities;
- promulgate the regulations to address disability discrimination under state grants and programs;
- serve as Virginia's Developmental Disabilities Planning Council for projects funded for persons with developmental disabilities;
- initiate a plan of cooperation between state agencies which provide services to persons with disabilities.

Board Membership

Name	Qualification	Occupation
Alan Bartel Virginia Beach	Parent of two sons who are hearing impaired, one of whom is also autistic	Cardiologist
Charles Bledsoe Jonesville	Primary consumer (muscular dystrophy)	Advocate
Nathanial Brown Charlottesville	Primary consumer (osteogenesis imperfecta)	Customer Service Supervisor/Warehouse, Centel
Marianne Cashatt Fishersville ▸ Board Secretary	Primary consumer (paraplegic)	Advocate
Helen Daniel Richmond	Parent of a child with down syndrome	Agency Management, Lead Analyst Dept. of Social Services
Harry Gewanter Richmond ▸ Health Chair	Parent of a child with attention deficit disorder, and a child with down syndrome	Pediatric Rheumatologist
Cheryl Heppner Reston	Primary consumer (hearing impairment)	Outreach worker Dept. for Deaf & Hard of Hearing
Donna Heuneman Virginia Beach ▸ Planning Chair	Parent of a child with cerebral palsy	Director, Tidewater Chapter of UCP
Maureen Hollowell Virginia Beach ▸ Board Chair	Parent of a child who is hearing impaired and has spina bifida	Advocate
Stephen Johnson Virginia Beach ▸ Transportation Chair	Primary consumer (spinal cord injury)	Executive Director, Norfolk Endependence Center
Martha Markham Bon Air	Primary consumer (head injury)	Pharmacist
E. Davis Martin Richmond	Parent of a child with a brain injury	Professor, Dept. of Rehabilitation Counseling, VCU
R. Randolph Mason Charlotte Courthouse	Parent of a child with autism	Pharmacist
Virginia McDaniel Richmond	Parent of a child with a learning disability	Nurse
Helena Payton Norfolk ▸ Housing Chair	Primary consumer (visual impairment)	Advocate
Lillian Pennell Fishersville	Primary consumer (spinal cord injury)	Retired Counselor
Elizabeth Perry-Varner Richmond	Primary consumer (epilepsy)	Executive Director Epilepsy Assoc. of Virginia
Doris Redwine Richmond	Primary consumer (mental health)	Manager of Virginia House (clubhouse)
W. B. Scott Chester	Primary consumer (paraplegic)	Advocacy Director, Paralyzed Veterans of Virginia
Ralph Shelman Hampton	Primary consumer (visual impairment)	Executive Director, Peninsula Center for Independent Living
Rev. Christine Shelton Richmond	Parent of a child with sickle cell anemia	Director, R-CAP Head Start Program
John Wells Virginia Beach	Primary consumer (mental retardation)	Founder, People First of Virginia Beach
Mary Margaret Cash Lynchburg ▸ Employment Chair	Citizen at Large	Advocate
Steven Stone Alexandria	Citizen at Large	Attorney

Other Representatives

Howard Sparks Richmond	Director of Virginia Institute for Developmental Disabilities
Wayne Speer Blacksburg	Representative of a Higher Education Training Facility (504 Coordinator — VA Tech.)
William Britton Providence Forge	Representative of a Local Government Agency
James Dill Covington	Representative of a Manufacturing Interest, Westvaco Corp.
Spencer Bartley Sterling	Representative of a Retailing Industry, Southland Corp.
Barbara Wolcott Virginia Beach	Representative of a Real Estate Interest
Sandy Modell Arlington	Representative of a Public Transit Interest, Downtown Alexandria Shuttle — D.A.S.H. Paratransit Services
Robert Steig Berryville ▸ Board Vice-Chair	Representative from a non-governmental agency concerned with services for persons with DD, Headmaster of Grafton School

Agency Heads

Lily Page Bess	Dept. for the Deaf and Hard of Hearing
Thelma Bland	Dept. for the Aging
Donald Cox	Dept. for the Visually Handicapped
King Davis	Dept. of Mental Health, Mental Retardation & Substance Abuse Services
Joseph Spagnolo, Jr.	Dept. of Education
Bruce Kozlowski	Dept. of Medical Assistance Services
Susan Urofsky	Dept. of Rehabilitative Services
James Rothrock	Dept. for Rights of Virginians with Disabilities

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